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DOI:
10.1016/j.burns.2018.10.020

The role of self-management in burns aftercare: a qualitative research study

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Abstract

Introduction

For severe burns patient care presents a considerable challenge, necessitating an integrated multi-disciplinary approach that utilises a range of treatments. The period of care post-discharge can be lengthy and complex, and include scar management, occupational and physiotherapies, psychological support, and further surgery. How successfully the patient negotiates this complex care regimen is critical to their long-term recovery and in doing so they would appear to employ approaches recognised as “self-management” in other chronic conditions. However their exact nature and how they are used has yet to be explicitly explored amongst chronic burn patients.

Methods

Semi-structured interviews were conducted with 24 patients to discuss their experiences of long-term burn treatment as part of a broader mixed-methods feasibility study of the use of pressure garment therapy in preventing hypertrophic scarring after burn injury. The topic guide included questions on the patient experience of their care post discharge, including pressure garment therapy and other scar management techniques; and their expectations and experiences of treatment and recovery. The data were analysed using an established framework of self-management processes.

Results

Burns patients employ many of the same processes of self-management as those experiencing more widely recognised chronic diseases or illnesses. This is despite the prospect of gradual improvement amongst burns patients absent in those with incurable chronic conditions. The key processes of self-management they share are the ability to focus on their illness needs, activate the appropriate resources and coming to terms with the consequences of living with either the physical or psychological consequences of their condition.

Conclusion

Modern burn care is technologically advanced and delivered by a highly trained, multi-disciplinary team, yet the level of its success relies on the ability of the patient to independently fulfil a number of health-related tasks and activities once leaving hospital. Considering the potential cost-savings to health services and the prospect of improved outcomes for patients capable of self-management our work is an important first step in more precisely understanding the use of self-management amongst burns patients, and the level of implicit or explicit support currently offered by their care providers.

1. Introduction

Some 250,000 individuals sustain burns in the UK every year with the potential of lasting impact on appearance, and psychological, social, and physical functioning [1]. For severe burns in particular, patient care presents a considerable challenge, necessitating an integrated multi-disciplinary approach and utilising a range of treatments [2]. Typically it consists of two distinct phases; the first acute phase is when the patient is hospitalised where beyond their initial survival, the key requisite is closing the wound [3]. The second phase consisting of rehabilitation and post-discharge management is termed “aftercare” [4] and addresses aesthetic, functional and psychological requirements [5]. This can last up to two years and is complex [6], using a combination of treatments that include scar management modalities (e.g. massage, creaming, pressure garment therapy); occupational and physiotherapies; psychological counselling, and further surgery [7]. Lack of adherence to these treatments has implications for the degree of scarring, [8] functionality [9] and psychosocial issues, [10] as well as cost implications for health care services [11]. Therefore, the aftercare period is critical in terms of the overall success of the treatment and the degree to which a functioning patient can rejoin society [12]. However despite its importance, patients and their carers are expected to negotiate much of this lengthy and complex care regimen independently with only intermittent contact with care providers.

Severe burns are technically defined as a chronic condition due to their effects lasting longer than three months [13]. However, this chronicity is not always recognised [6] despite the lasting impact on physical appearance and capability, and the psychological implications of long-term treatment, being similar in nature to that experienced by those with more widely recognised chronic disease or illness [14]. Similarly the obstacles burns patients face in maintaining their aftercare in the years following the injury, that include depression, fatigue, dependence on family support, and financial problems [15-18] are also comparable to those experienced by patients with other chronic

conditions [19]. However, for those with diseases such as type II diabetes or hypertension, there is an understanding of how these obstacles can be mitigated by the use of "self-management" [20], defined as "the ability of the individual in conjunction with family, community, and healthcare professionals to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions." [21]. This self-management is frequently supported by the training and education of patients that encourages problem solving, decision making, and appropriate use of resources [20] and has led to improved patient engagement, adherence, and efficiency of healthcare utilisation [22-24].

Research exploring burns aftercare has described how patients need to adapt to the long-term consequences of their injury (25). The ways in which patients may try to achieve this have been conceptualised as self-management processes in other chronic conditions, but to date there has not been an explicit focus on self-management processes in burns aftercare. It is possible that if acknowledged and understood these processes can be better supported with the potential to benefit burns patients and healthcare services. First, however there is the need for a better appreciation of which if any self-management processes are being employed by patients with severe burns and in which context. Here we present data from a comprehensive exploration of patient perspectives of burn aftercare conducted as part of a feasibility study for a trial of scar management regimes [26] with the aim of establishing whether burns patients describe the self-management processes that are widely recognised in other chronic conditions.

2. Methods

2.1. Study design

This qualitative research was a part of a broader mixed-methods feasibility study of Pressure Garment Therapy (PGT) for the prevention of hypertrophic scarring after burn injury in adults and children (The PEGASUS Study) [26]. One aim of the qualitative research was to understand adult patients' experiences of scar management therapies, and predominantly PGT.

2.2. Sampling and recruitment

The sample consists of adult patients who were participants in a pilot trial of PGT that formed part of the PEGASUS study. Patients participating in the pilot trial were allocated to scar management with or without PGT. Participants were recruited by occupational therapists (OTs) and/ or research nurses (RNs) in 3 of the PEGASUS pilot trial sites in the West Midlands and South East Regions of England. Clinical staff provided information sheets to potential interviewees and took written consent to pass participant contact details on to the PEGASUS qualitative research team. A member of the qualitative research team then contacted potential interviewees, provided further information and answered questions as necessary, before arranging a suitable time, date and venue for the interview. Written informed consent was received from all participants prior to the start of data collection. Participants were interviewed at two time points, soon after consent to participate in the trial and allocation to treatment, and then 9-12 months later. The data utilised here comes from the later interviews, undertaken at a stage when participants had significant experience of burns aftercare and scar management.

2.3. Ethics

Ethics approval for the PEGASUS study was received from the West Midlands: Coventry and Warwickshire Research Ethics Committee (14/WM/0160).

2.4. Data collection

Semi-structured interviews were conducted by IL and JM who are experienced non-clinical qualitative researchers who were independent of the participants' clinical care team. Interviews were conducted in the patient's home, or via telephone. A semi-structured discussion guide was developed based on the literature, discussions with our patient and public involvement (PPI) group, and the wider PEGASUS research team. The semi-structured interviews were conducted in a participant-focused manner allowing issues and perspectives important to participants to emerge naturally. Topics discussed included: accounts of the accident and injury (where participants were happy to talk about these in order to provide context for the remainder of the discussion); accounts of subsequent treatment; the experience of PGT and other scar management techniques; hopes and expectations for treatment, recovery and scar management; perspectives on the pilot trial of PGT including trial processes and assessments, and patient-centred outcomes. The topic guide and interview process was refined over the first 3 interviews. Following this, data collection and analysis took place iteratively. At the end of each interview, participants were asked to complete a short demographic questionnaire to facilitate maximum variation sampling and a description of the sample characteristics. We attempted to include a range of patients according to sex, age, ethnicity, type and severity of burn, and allocation to scar management with or without PGT.

2.5. Data analysis

Interviews were digitally audio-recorded and transcribed clean verbatim by a specialist company. In order to establish whether burns patients describe the use of self-management processes that are recognised in other conditions we applied a framework of self-management processes developed by Schulman-Green et al (2012) to the interview data (27). This framework is based on a meta-synthesis of 104 qualitative research papers that have explored self-management from the perspective of chronically-ill patients. There are a number of other existing frameworks that have been used to describe the processes of self-management [20, 28- 31]. However, the Schulman-Green study was the first to define these processes solely from the perspective of patients living

with chronic illness. The three key processes they identified were; 1) ***Focussing on illness needs***; 2) ***Activating resources***; and 3) ***Living with a chronic condition*** (Table 1).

A sample of interviews were analysed separately by two of the authors (IL & JM). Any discrepancies were resolved via discussion and the overall interpretations presented here were discussed and agreed with all authors. We do not claim to have reached data saturation in relation to participants' use of self-management processes and techniques (32). The interviews were broad ranging and the intention of this paper is to illustrate that patients are utilising processes conceptualised as self-management in other disease areas, not to provide a comprehensive theory of self-management in burns.

144 **Table 1. Key processes and sub-processes, including definitions (taken from Schulman-Green et al).**
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3. Results

We interviewed a total of 24 patients, with equal numbers from each clinical site. The majority were male and had experienced burns from direct contact with flames. The characteristics of patients are summarised in Table 2 including their age group, the type of burn and total body surface area burned.

Table 2: Sample characteristics

Not every sub-process identified by Schulman-Green was observed in our cohort but those shared by the burns patients we spoke to are described below alongside exemplar quotes.

3.1. Focussing On Illness Needs

The first process of self-management requires patients understand the parameters of their disease or condition and its treatment. They look to learn about their diagnosis, understand and assume responsibility for the implications on their lifestyle, and undertake related health promotion activities.

3.1.1. Learning

Patients successfully self-managing their chronic disease acquire information about their condition and learn the requisite regimens and skills to manage their daily illness needs. Our participants undergo a similar process as they learn to manage their condition and recovery. This includes understanding the prognosis of their injury and the implications of their particular burn and how these might be mitigated, for example, via additional surgical interventions. One patient described the process of cording (feeling of tightening), which can occur following a skin graft when lymph vessels become clotted, and how this necessitated further surgery to increase functionality:

So that's like cording, so I don't know if you know about skin grafts?...Can you see the way it pulls, like that?...This does that here, wearing the garment on my torso won't help that but there, that needs some more Z-plasties done, some more operations just to get that to stretch even more, West Midlands, Male, (Participant ID) P16

3.1.2. Taking ownership of health needs

Patients with chronic disease learn to manage their symptoms and body responses and the patients we spoke to described how they monitored and managed symptoms of their burn injury and adjusted their treatment accordingly. One example is how they applied moisturiser to their skin to prevent the scar site from tightening. Patients also described the changes in sensitivity of the burn site in terms of its tactile responses to different materials or its reaction to sunlight:

Yes, it's just my fingertips I have to be careful how I touch things, different materials, metals I have to be careful with, and it's the sun as well, I have to really be careful in the sun, ever so sensitive to the sun, factor 50 all the time. West Midlands, Male-P12

As part of their care, patients with chronic disease are required to complete a number of related health tasks including taking their medication. In the same way burns patients have to complete certain activities as part of the recovery process including taking a specific combination of analgesics or regularly administering moisturiser:

Got up in the morning and washed it and creamed it. I made sure I did that all the time, took their advice. West Midlands, Male-P15

Failure to attend appointments is a common issue in the NHS and though it may appear to be a straightforward process, organising and managing responsibilities in order to ensure attendance can

be complicated by a number of social or clinical factors. In the same way that those with chronic conditions need to regularly attend clinical reviews as part of the ongoing management of their condition, patients with serious burns also have to attend regular appointments at specialist clinics. That there are only a handful of these burns units across the UK means that many patients are required to travel long-distances and utilise considerable resource:

> *So it does take a big chunk of my day out because I have to take the day off from work,...it takes you half a morning just to get there and back and have the treatment and sometimes it takes longer and you end up being left two hours waiting or something. So it has cost me a lot of money in terms of petrol and getting there and parking and stuff, but on saying that…[the staff] have been brilliant.* Sussex, Female-P01

Over time the ability of patients with chronic illness to manage their condition improves as their experience and expertise increases. A similar increase in expertise was demonstrated by the burns patients we spoke to who described how they adjusted their treatment over time to achieve a particular goal. The prescription for pressure garments is typically to wear them for 23 hours a day however for patients with skin grafts sensitisation can be an issue exacerbated by these lengthy periods wearing the garment. Desensitisation requires re-training the nervous system to accept mild-touch and to facilitate this process nurses can encourage patients to reduce the time they are wearing the garment at the patient's discretion. One patient described how they gradually decreased the number of hours they would wear their pressure garment as they successfully reduced sensitisation of their burn site:

> *The garments are great, but I can't go for more than… well actually if you had spoken to me about a month or so ago it would have been about an*

hour but now I can actually go without them for maybe half a day. But that's because I'm trying to desensitise the scars, so I actually sleep without it now… Essex, Female-P02

Another patient spoke of the issues they encountered with itching around the site of the healing injury. Aware of the sensitivity of the area and the importance of not disturbing the scar by direct contact a patient described how they learnt to manipulate the area through their pressure garment using escalating degrees of force and ultimately resorting to cold water when the itch was at its most relentless:

Yes it does itch and I find a way around it, rub my hand over the actual pressure garment itself, and then if it does become a bit too intense that itchy sensation I just itch over on top of the actual pressure garment, so I'm not actually impacting any of the skin underneath, and worse comes to worse I'll run it under cold water, the cold water shocks the skin into something else. Essex, Female-P01

3.1.3. Performing health promotion activities

Chronically ill patients would be required to make alterations to even the most routine activities to minimise the impact of their condition. The same was observed in our participants who reported benefits from what appear quite minor changes. For example one patient slept with an additional duvet to minimise the disruption to their sleep caused by aggravating the sensitive injury:

I was sleeping in the same bed but he had the double duvet and I had a single duvet on me, because him rolling over and moving the duvet would wake me up and make me cry. Essex, Female-P02

3.2. Activating Resources

To optimise any self-management regime resources associated with the healthcare system or derived socially from friends and family must be accessed. These resources assist individuals in managing both the medical and psychosocial aspects of their condition.

3.2.1. Healthcare resources

The activation of healthcare resources can vary in intensity and complexity dependent upon the individual and the severity of their illness or condition. One aspect of this, recognised in chronically ill patients and also seen in burns patients, is the collaborative relationship developed with their care providers. Our patients described how they would contribute to decisions affecting their care regime. For example one patient spoke of working together with their occupational therapist in re-designing a pressure garment so that it was more comfortable and delivered pressure more effectively:

> *Between me and the occupational therapist we devised one, … that actually is an all in one and does up under the crotch, and a) that gives me better compression because it stays still, and b) it's more comfortable because I'm not pulling it down all the time.* Essex, Female-P02

3.2.2. Social resources

The social resources activated are individual to each patient and can vary over time dependent on availability and requirements, as their condition and needs change. There are a number of recognised sources of such support activated by chronically ill patients, including family and friends. Our participants also recalled how they relied on family members during their recovery for example in transportation to the clinic during the early part of their recovery:

I've got a really good support service with my family, and once I could drive that was it. But I was being taken either by my daughter or by my mum, and then once I was driving I would drive myself. Essex, Female-P02

Participants also spoke of the psychological support derived from their family. The same patient described the increased value attached to the feedback of trusted family members, perceived as being unencumbered by the same social conventions that might moderate the responses of their friends:

I don't know if it's helped my scars but people that see them are my friends, and of course they're going to say they look great. But my children… my girls are a little bit more… they're 21 and 17 and they can't hide their faces, and they actually say that it's all looking great and how soft it is. Essex, Female-P02

3.2.3. Psychological resources

Those with chronic diseases are sometimes required to draw on their psychological resources to manage their condition. Participants also demonstrated this same ability to use their own resources to remain positive and focus on their recovery:

I always said when I was in hospital I'm going to control this whole situation, I'm not going to let this situation control me…. Unfortunately my stump has decided to take control, because it means it's going to grow out, it's going to be awkward,… Once the operation is out of the way and they've sorted that out then I'm back in control, I can start the physio, I

can start doing my walking, and I can nail it then … I'll just bide my time a bit more. West Midlands, Male-P13

3.3. Living With A Chronic Illness

The final process of self-management describes how patients come to terms with their chronic condition, learning to cope with their illness and integrating it into the context of their life. The burns patients we spoke to appeared to undergo a similar transition and described how they came to process their emotions, and adjust to and integrate their condition into their daily lives, ultimately making meaning of what has happened to them.

3.3.1. Processing emotions

Dealing with the psychological consequences of their condition is an important part of self-management in the chronically ill, part of which requires that patients explore and express various emotions relating to their diagnosis, including grieving and loss. We observed this in our interviewees who described the anguish of coming to terms with their scars as the long-term impact of the injury became apparent. One patient described the length of time it took before they addressed how they felt about their altered appearance:

When I was in hospital I said to my wife and everybody 'I don't care what it looks like, I don't care about the scars, it doesn't bother me.' But it did! At the time it didn't…but then it wasn't until a couple of months afterwards….I'm looking and I think 'I can't fucking believe this - what I look like.' and…it hit me … 'I do care what it looks like, I really do!' West Midlands, Male-P16

3.3.2. Adjusting

In adjusting to a new-self patients often use coping strategies. In burns patients these can be employed to help deal with the visual impact of their injuries. One patient used "self-talk" and created nicknames for each of three burn sites based on their appearance or sensitivity:

> *…the underarm one was called 'The Camembert', because that's what it looked like, it looked like soft cheese, and then the one right under my forearm where it's still sensitive is called 'The Chevron of Hate', and then I've got a flash one on my shoulder, that's 'The Harry Potter' [laughter]* Essex, Female-P02

Those with chronic conditions have to deal with the stigma associated with either the condition itself or its treatment. For our participants much of this stigma surrounded the change in appearance and a patient described how they had come to terms with that:

> *No, when I say it bothered me, it was more the look of them do you know what I mean? Going out and about and stuff like that, the sun shining walking round with a pair of bloody gloves on like, and you just look like a plonker. But yes it doesn't matter does it, it doesn't matter.* West Midlands, Male-P12

3.3.3. Integrating illness into daily life

The process of integrating their illness into their daily life and routines requires patients balance the pursuit of meaningful activities with the needs of their illness. Modifying lifestyles for the chronically ill frequently involves the creation of consistent health management routines. In the same way burns patients would create routines to help them comply with their prescription. One patient

explained how they had learnt to dress in the morning in a specific order to ensure that they wore their pressure garment for the specified period of time:

> *Yes, it's just second nature now; I put the garment on before I put my socks on. I think it will be strange not to have it now.* Sussex, Female-P05

The process of modification requires chronically ill patients exercise flexibility in their approach as they resume usual activities. Study participants also understood that they needed to be flexible as they sought to maintain patterns of behaviour followed before their injury. This type of adjustment was also found in our cohort with one patient describing how their return to work was predicated on amending the range and length of the tasks they performed:

> *I started to sneak in about four weeks later just for an hour or two…and then I think it was about four or five weeks, maybe five/six weeks after, I said "I'm going to do a full day at work today and see how I get on", …I didn't stay off work again. I work in - did work - half my time in the machine shop, half my time in the office, but it's been office more than anything. I walk around the machine shop but I don't do any lay work or anything now…* West Midlands, Male-P15

3.3.4. Meaning making

Ultimately chronically ill patients attempt to make sense of what has happened to them and gain meaning as a way of moving forward with their lives. They can use their condition as a learning process becoming empowered as they gain a greater understanding of their body and its responses and the prospects that remain to live a fulfilling life. Participants spoke of their desire to return to work even in a limited capacity or how alternative opportunities to those which existed prior to the

injury might be pursued. For example one patient we spoke who prior to the injury planned on serving on the front line for the army discussed the possibilities that still remained to work for the military albeit in a logistics role:

> *Hopefully join up for something in the military if I can. My boss says, "There will be hundreds of jobs for you, you could be logistics, driving, just doing the driving and stuff like that..." I said, "Yes I don't mind doing a bit of that." He said, "…anything, you won't be frontline, you won't be jumping out of a DC130 behind enemy lines, not like you were going to…but at the end of the day if you're bringing home a good wage and whatnot…don't worry about it." … So I would be happy* West Midlands, Male-P13

Another patient we spoke to appeared philosophical after their injury and described how they felt lucky their situation wasn't worse. Instead they used the memory of their accident to remind them to treat fire with respect, content in the knowledge that they were still alive.

> *At first you don't realise, but then you think to yourself "Jesus Christ it could have been right worse!". But luckily it wasn't, and we live another day, and put it behind you. But say put it behind you, I always keep it, I don't walk about 24/7 thinking about it, but I respect fire and everything.* West Midlands, Male-P16

4. Discussion

Modern burn care is technologically advanced and delivered by a highly trained, multi-disciplinary team yet the level of its success ultimately relies on the ability of the patient to independently fulfil a

number of health related tasks and activities once leaving hospital [2]. That this recovery can take in excess of three months means severe burns are defined as a chronic condition [13]. Self-management is an important concept in the current care model for many patients with similar long-term conditions [33]. It can provide them with the self-confidence to achieve the outcomes important to them [34], to experience better clinical outcomes [35], and allow care providers to have more meaningful conversations with their patients [36]. For the first time our thematic analysis has drawn attention to how burns patients employ many of the same processes of self-management as those experiencing more widely recognised chronic diseases or illnesses [27]. Our participants used examples of all three key self-management techniques namely they focused on their illness needs, activated the appropriate resources and began to come to terms with the consequences of living with the physical and psychological consequences of their condition.

4.1. Strengths/limitations

We offer a novel perspective on burns care, describing the similarities between the self-management processes used by those with more widely recognised chronic disease and those employed by patients with severe burns. The qualitative dataset we analyse here is drawn from one of the largest exploration of burns aftercare yet conducted in the UK. During the primary analysis of this data, collected as part of the final phase of the Pegasus study [26], it appeared burns patients were employing some of the self-management strategies described by patients experiencing chronic disease. The secondary analysis we present here is not intended to be exhaustive and the topic guide was not designed to explore self-management processes. Nevertheless these processes were evident and drawn from patients with a range of characteristics and burn types that we would suggest are potentially reflective of the broader population of burns patients.

4.2. Specific findings

4.2.1. Focusing on illness needs

Patients with chronic disease focus on their illness needs and develop expertise in managing their condition as they learn how to recognise and ameliorate their symptoms by making independent yet informed decisions on their care regimen as seen in patients with psoriasis [37] or type 1 diabetes [38]. For burn care to be successful patients need to assume a degree of responsibility for managing their wound and their physical and mental health once leaving the hospital. This begins with understanding more about their condition. Some of those we interviewed described how they had learnt to adjust their treatment as their recovery proceeded. For example, one common yet fluctuating side-effect of burn recovery are multiple episodes of acute pruritis [39] and patients in our study described how they developed strategies to reduce its impact.

4.2.2. Activating resources

Self-management of chronic disease requires the establishment and maintenance of relationships with care providers as patients navigate the healthcare system and access appropriate resource [27]. This behaviour previously observed in patients with chronic disease such as type II diabetes [40,41] was also described by our interviewees who attended appointments throughout their aftercare with a range of consultants, nurses, and therapists. In line with previous research with burns patients [40] our participants also reported the benefits of developing rapport with their healthcare provider over the course of their treatment.

As well as effectively accessing health care resources the utilisation of social resource also plays an important role in the self-management of a variety of chronic diseases [42] and conditions [43]. Our participants also spoke of the value of the support gained from friends and family, particularly in the

453 early stages of their recovery. Previous work with burns patients has described how support of this
454 nature improved their quality of life [44], and provided motivation to recover [45] and it is perhaps
455 worth noting that this support may be particularly salient for burns patients, a group vulnerable to
456 depression and mental ill-health [46,47].
457

458 *4.2.3. Living with a chronic condition*

459 Ultimately successful self-management requires chronically ill patients learn to live with their
460 condition or disease, developing strategies to help them cope and ultimately integrate the
461 management of their disease into their everyday life. Such strategies observed in patients with
462 chronic heart failure [48] or white lymphedema [32] may be equally influential in the rehabilitation
463 journey of burns patients [45,34] though have not previously been explicitly recognised as a self-
464 management process. For example one of our participants described how they enabled their
465 prompt return to work by adjusting the parameters of their role to account for their physical
466 limitations. This modification of activity has not only been observed in other burns patients [25] but
467 also in patients with chronic obstructive pulmonary diasease [49] and multiple sclerosis [50].
468

469 For those left disfigured or functionally limited by serious burns, acknowledgement and acceptance
470 play an important part in their recovery [25]. The process of acceptance is equally important for
471 those diagnosed with long-term conditions such as chronic heart failure [48]. Humour and self-
472 awareness evident in “Self-talk” contributes to this [48] and was evidenced in our patients with one
473 patient creating nicknames for each of their scars.
474

475 *4.2.4. Support of self-management*

The adoption of self-management is not uniform across all patient groups and is influenced by factors including the severity of the disease or condition [51,52], the ability of patients to embed solutions into everyday practice [53,54], and the available support of family and healthcare providers [55,56].Frequently in other long-term conditions or illnesses structured support is provided to help sustain self-management and is a central part of many of the health and social care policies being employed across the UK [35; 57-59]. This support incorporates training not only for patients and carers but also health care professionals, and involves peers and community groups and the organisational systems necessary to underpin patient self-management [60]. Where appropriate support is in place and embedded in commissioning and planning it has been demonstrated to improve levels of self-management for those with chronic disease [61,62].

4.3. Conclusions

Before targeted self-management support can be considered for burns patients further work is needed to understand more accurately its prevalence amongst burns patients, the level of implicit or explicit support currently offered by their care providers and the suitability of existing systems to underpin it. Ultimately interventions might be usefully introduced to bolster these processes; in the meantime our findings at least begin to raise awareness of the *ad hoc* self-management processes currently used by patients with severe burns and will encourage discussion on the level of existing support offered to patients post-discharge.

Conflict of interest statement

All named authors declare that there are no known conflicts of interest relating to this manuscript.

Funding

This project was funded by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Programme (project number 12/145/04) and will be published in full in the HTA journal series.

This report presents independent research commissioned by the NIHR. The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, MRC, CCF, NETSCC, the HTA programme or the Department of Health.

The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, MRC, CCF, NETSCC, the HTA programme or the Department of Health.

Acknowledgements

We would like to thank the patients who kindly participated in the research interviews that form the basis of this work. We would also like to acknowledge the contribution of the clinical staff who helped recruit participants to the Pegasus study.

REFERENCES

1. Falder S, Browne A, Edgar D, et al. Core outcomes for adult burn survivors: a clinical overview. Burns. 2009;35(5):618-41.

2. Al-Mousawi AM, Mecott-Rivera GA, Jeschke MG, et al. Burn teams and burn centers: the importance of a comprehensive team approach to burn care. Clin Plast Surg. 2009;36(4):547-54.

3. International Best Practice Guidelines: Effective skin and wound management of non-complex burns. Wounds International 2014

4. Van Loey NE1, Faber AW, Taal LA. Do burn patients need burn specific multidisciplinary outpatient aftercare: research results. Burns. 2001 Mar;27(2):103-10.

5. S. Rea, F. WoodMinor burn injuries in adults presenting to the regional burns unit in Western Australia: a prospective descriptive study Burns, 31 (2005), pp. 1035-1040

6. Christiaens W, Van de Walle E, Devresse S, et al. The view of severely burned patients and healthcare professionals on the blind spots in the aftercare process: a qualitative study. BMC Health Serv Res. 2015;15:302.

7. Anthonissen M, Daly D, Janssens T, et al. The effects of conservative treatments on burn scars: A systematic review. Burns. 2016;42:508-18.

8. So K, Umraw N, Scott J, Campbell K, Musgrave M, Cartotto R Effects of enhanced patient education on compliance with silicone gel sheeting and burn scar outcome: a randomized prospective study. J Burn Care Rehabil. 2003;24(6):411-7;

9. Esselman PC Burn rehabilitation: an overview Arch Phys Med Rehabil. 2007;88(12 Suppl 2):S3-6

10. Hop MJ1, Polinder S, van der Vlies CH, Middelkoop E, van Baar ME Costs of burn care: a systematic review. Wound Repair Regen. 2014;22(4):436-50. doi: 10.1111/wrr.12189.

11. Fletchall S1, Hickerson WL.Fletchall and Hickerson Quality burn rehabilitation: cost-effective approach. J Burn Care Rehabil. 1995;16(5):539-42.

12. Takayanagi K, Kawai S, Aoki R. The cost of burn care and implications for efficient care. Clin Perform Qual Health Care 1999;7(2):70–3.

13. National Center for Health Statistics, Centers for Disease Control and Prevention. (2013) Summary Health Statistics for the U.S. Population: National Health Interview Survey, 2012.

14. Goodman RA, Posner SF, Huang ES, Parekh AK, Koh HK. Defining and Measuring Chronic Conditions: Imperatives for Research, Policy, Program, and Practice. Prev Chronic Dis 2013;10

15. Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self management of chronic conditions. Patient Educ Couns 2005;57:300-307.

16. Oster C, Kildal M, Ekselius L. Return to work after burn injury: burn-injured individuals' perception of barriers and facilitators. J Burn Care Res. 2010;31:540-550.

17. Ripper S, Renneberg B, Landmann C, Weigel G, Germann G. Adherence to pressure garment therapy in adult burn patients. Burns. 2009;35:657–664.

18. Gonçalves N, Echevarría-Guanilo ME, de Carvalho FE, Miasso AI, Rossi LA. Biopsychosocial factors that interfere in the rehabilitation of burn victims: integrative literature review. Fatores biopsicossociais que interferem na reabilitação de vítimas de queimaduras: Revisão integrativa da literatura 2011;19:622–630.

19. Larsen p. Chronicity. In: Lubkin IM, Larsen PD, editors. Chronic Illness: Impact and Intervention. 7th ed. Jones and Bartlett; Boston, MA: 2009. pp. 3–24

20. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms Ann Behav Med 2003;26:1-7.

21. Richard AA, Shea K J Delineation of self-care and associated concepts. Nurs Scholarsh. 2011 Sep; 43(3):255-64. p261

22. Horwitz RI, Horwitz SM. Adherence to treatment and health outcomes. Arch Intern Med 1993;153:1863-1868.

23. Horwitz RI, Viscoli CM, Berkman L, et al. Treatment adherence and risk of death after a myocardial infarction. Lancet 1990;336:542-545.

24. S. Nolte, G. Elsworth, A. Sinclair, R.H. Osborne The extent and breadth of benefits from participating in chronic disease self-management courses: a national patient-reported outcomes survey Patient Educ Counsel, 2007; ;65(3):351-60.

25. Kornhaber RA, Wilson A, Abu-Qamar MZ. Coming to terms with it all: adult burn survivors' 'lived experience' of acknowledgement and acceptance during rehabilitation. Burns. 2014;40(4):589-97.

26. National Institute for Health Research (2013) HTA – 12/145/04: a feasibility study and open pilot two-arm randomised controlled trial comparing Pressure Garment Therapy with no Pressure Garment Therapy for the prevention of abnormal scarring after burn injury (PEGASUS).

27. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. J Nurs Scholarship 2012;44(2):136-44.

28. Corbin JM, Strauss A. Unending work and care: Managing chronic illness at home. San Francisco, CA: Jossey-Bass; 1998.

29. Dunbar SB, Clark PC, Quinn C, Gary RA, Kaslow NJ. Family influences on heart failure self-care and outcomes. J Cardiovasc Nurs 2008;23(3):258-265.

30. Grey M, Knafl K, McCorkle R. A framework for the study of self and family management of chronic conditions. Nurs Outlook 2006;54(5):278-286.

31. Ryan P, Sawin KJ. The Individual and Family Self-Management Theory: Background and perspectives on context, process, and outcomes. Nurs Outlook 2009;57(4):217-225.

32. Saunders, B., Sim, J., Kingstone, T. , Baker S, Waterfield J, Bartlam B, Burroughs H, Jinks C. Qual Quant (2018) 52: 1893. https://doi.org/10.1007/s11135-017-0574-8

33. Bogan LK, Powell JM, Dudgeon B J. Experiences of living with non-cancer-related lymphedema: Implications for clinical practice. Qual Health Res 2007;17:213-224.

34. Dahl O, Wickman M, Wengstrom Y. Adapting to life after burn injury-reflections on care. J Burn Care Res 2012;33:595–605.

35. National voices, prioritising person-centre care supporting self-management 2014]

36. Kidd L, Lawrence M, Booth J, Rowat A and Russell S (2015) Development and evaluation of a nurse-led,tailored stroke self-management intervention. BMC Health Serv Res 15, 359

37. Ersser SJ, Cowdell FC, Latter SM, Healy E. Self-management experiences in adults with mild-moderate psoriasis: An exploratory study and implications for improved support. Br J Dermatol 2010;163:1044-1049. (5): 347–50.

38. Paterson B, Thorne S. Developmental evolution of expertise in diabetes self-management. Clin Nurs Res 2000;9(4):402-419.

39. Ahee AM, Smith SJ, Pliska-Matyshak G, Cullen ML. When does itching start and stop post-burn? J Burns Care Rehabil 1999;20:S187.

40. Furler J, Walker C, Blackberry I, et al. The emotional context of self-management in chronic illness: A qualitative study of the role of health professional support in the self-management of type 2 diabetes. BMC Health Serv Res 2008;8:1-9.

41. Esselman PC. Burn rehabilitation: an overview. Arch Phys Med Rehabil 2007 Dec;88(12 Suppl 2):S3-6.

42. Hwang EJ, Kim YH, Jun SS. Lived experience of Korean women suffering from rheumatoid arthritis: a phenomenological study. Int J Nurs Stud 2004;41:239-246.

43. Lee AM, Poole G. An application of the transactional model to the analysis of chronic illness narratives. Qual Health Res 2005;15:346-364.

44. Rossi L, Silva Costa M, Dantas R, Ciofi-Silva C, Lopes L. Cultural meaning of quality of life: perspectives of Brazilian burn patients. Disabil Rehabil: Int Multidis J 2009;31:712-719.

45. Moi A, Gjengedal E. Life after burn injury: striving for regained freedom. Qual Health Res 2008;18:1621-1630.

46. Wiechman SA. Psychosocial recovery, pain, and itch after burn injuries. Phys Med Rehabil Clin N Am 2011;22(2):327-45.

47. Sheridan RL. Burn rehabilitation. Medscape. 2016. Available at: http://emedicine.medscape.com/article/318436-overview (accessed March 2017).

48. Bennett SJ, Cordes DK, Westmoreland G, Castro R, Donnelly E. Self-care strategies for symptom management in patients with chronic heart failure. Nurs Res 2000;49:139-145.

49. Cicutto L, Brooks D, Henderson K. Self-care issues from the perspective of individuals with COPD. Patient Educ Couns 2004;55:168-176.

50. Courts NF, Buchanan EM, Werstlein PO. Focus groups: The lived experience of participants with multiple sclerosis. J Neurosci Nurs 2004;36:42-47.

51. Riley JP, Gabe JP, Cowie MR. Does telemonitoring in heart failure empower patients for self-care? A qualitative study. J Clin Nurs 2013;22(17-18):2444–55.

52. Or CK, Karsh BT, Severtson DJ, Burke LJ, Brown RL, Brennan PF. Factors affecting home care patients' acceptance of a web-based interactive self-management technology. J Am Med Inform Assoc 2011;18(1):51-9.

53. Taylor DM, Stone SD, Huijbregts MP. Remote participants' experiences with a group-based stroke self-management program using videoconference technology. Rural Remote Health 2012;12:1947.

54. Fex A, Flensner G, Ek AC, Soderhamn O. Self-care agency and perceived health among people using advanced medical technology at home. J Adv Nurs. 2012;68(4):806-815.

55. Austin SA, Claiborne N. Faith wellness collaboration: a community-based approach to address type II diabetes disparities in an African-American community. Soc Work Health Care. 2011;50(5):360–75. doi:10.1080/00981389.2011.567128.

56. Shaw SJ, Armin J, Torres CH, Orzech KM, Vivian J. Chronic disease self-management and health literacy in four ethnic groups. J Health Commun. 2012;17 Suppl 3:67–81. doi:10.1080/10810730.2012.712623.

57. Gaun Yersel; Scotland http://www.gov.scot/Resource/0042/00422988.pdf accessed July 2017

58. Living with long-term conditions in Northern Ireland https://www.health-ni.gov.uk/publications/living-long-term-conditions-policy-framework accessed August 2017

59. Designed to Improve Health and the Management of Chronic Conditions in Wales http://www.wales.nhs.uk/documents/Chronic_Conditions_English.pdf accessed August 2017

60. The coalition for collaborative care NHS England http://coalitionforcollaborativecare.org.uk/ accessed August 2017

61. Dwarswaard J, Bakker EJ, van Staa A, Boeije HR. Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. Health Expect 2016;19(2):194-208.

62. Kennedy A, Rogers A, Bower P. Support for self care for patients with chronic disease BMJ 2007; 335 :968